

HB 5212  
Thomas Stolper  
February 25, 2010

PREPARED TESTIMONY IN SUPPORT OF RAISED BILL NO. 5212:  
"AN ACT CONCERNING INSURANCE COVERAGE FOR THE TREATMENT OF  
BLEEDING DISORDERS."

Treatment of the bleeding disorder with which I was born (classical hemophilia A, factor 8 deficiency) requires intravenous infusion of the missing blood factor as soon as possible after a bleed begins.

Any delay results in unnecessary injury, and in the need to use much more factor than in the case of prompt treatment. Time is of the essence.

Infusable factor concentrates didn't become available until the latter 1960s, so my joints were badly damaged by repeated bleeds in childhood and adolescence. Thanks to the factor concentrates introduced after 1965, children today don't have to deal with that.

As with many other rare diseases, the medicine is so specialized that even today, only hospitals at the top of medical totem pole keep a supply on hand.

Although I have been fortunate to live near such a hospital for most of my adult life (and still do), I was urged long ago, by the doctors and nurses who looked after my case, to learn how to self-infuse, to keep a supply of the medicine at home, and to take some with me when I traveled. I began doing so around 1971, in other words, since I was around 30 years old.

The model of treatment pioneered by the Hemophilia Treatment Centers (HTCs) mentioned in the bill has been highly successful, and I hope that the HTCs will continue to be supported.

Having access to an HTC has been important to me for decades. The HTCs give one access not only to doctors and nurses experienced with bleeding disorders, but also to a top-flight coagulation laboratory.

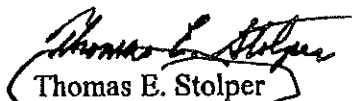
Access to a full range of factor 8 products is also important, and the HTCs know which ones will work best for which patients. The HTCs provide timely authorizations to the pharmacies.

I have been fortunate to have had access to the new, safe, very pure recombinant products almost from the time they were first introduced some 20 years ago. I don't use the newest and most expensive product, because the next one down the line is excellent and has been working for me for years; but I wouldn't want to be forced to use a blood-derived product again just because it was cheaper.

Any chronic disease is expensive, so help with insurance reimbursement is appreciated, and I have had that, too, from the specialized home-care pharmacy that was founded by an old acquaintance and of which I have been a client for many years.

I hope that the General Assembly of the State of Connecticut will pass Raised Bill No. 5212.

Thank you for your consideration of this matter.

  
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